

Preliminary Program

National Center on Birth Defects and Developmental Disabilities

**Conference
July 26-28, 2004**

Navigating Our Future: Aligning Strategies and Science

Omni Shoreham Hotel
Washington, DC





Centers for Disease Control and Prevention National Center on Birth Defects and Developmental Disabilities 2nd Conference *Navigating Our Future: Aligning Strategies and Science*

Please plan to join your colleagues at the 2nd conference sponsored by the National Center on Birth Defects and Developmental Disabilities (NCBDDD), Centers for Disease Control and Prevention (CDC), to be held at the Omni Shoreham Hotel, Washington, D.C., July 26-28, 2004. Over 1,200 health professionals and others are expected to attend. The conference is large enough to address a broad range of interests, yet small enough to enable participants to meet speakers and network with other participants.

Conference Themes

- Promoting early identification of genetic and developmental conditions.
- Understanding the causes, occurrence, and consequences of birth defects, developmental disabilities and heritable blood disorders.
- Preventing birth defects and developmental disabilities.
- Reducing secondary conditions among people with disabilities and heritable blood disorders.
- Promoting health and well-being among persons with disabilities.
- Translating knowledge about prevention to public health policy and programs.
- Promoting cutting-edge science, particularly, in defining biomarkers of exposure or disease and examining environmental and genetic interactions.

Conference Goals

- Provide a forum for input into the NCBDDD strategic plan and research agenda.
- Identify and share cutting edge science in NCBDDD disease prevention activities.
- Facilitate collaboration among NCBDDD's various partners in achieving its strategic agenda.

Who Should Attend

- Physicians, nurses, health educators, epidemiologists, statisticians, behavioral scientists, health communication specialists, evaluation specialists, health economists.
- Public health professionals in government at the local, state and federal level.
- Academic and research staff from educational institutions.
- Managers, directors, and executives from voluntary and health professional associations.
- Representatives from managed care organizations.
- Representatives from special interest groups, business and industry.
- International health professionals, managers, and researchers.
- Other nongovernmental health professionals, consultants and students.

Conference Highlights

- Keynote addresses by national leaders, dignitaries, and others.
- Plenary sessions on major birth defects, developmental disabilities, bleeding disorders, and disability and health issues.
- Concurrent sessions on specific, high-priority topics.
- Creative partnering.
- Communicating with policy makers and creating policy change.
- Emerging issues.
- Translating research to practice.
- Research and evaluation methods for new initiatives.



Plenary Highlights

Day 1

Opening Plenary

José F. Cordero, M.D., M.P.H, Director of the CDC's National Center on Birth Defects and Developmental Disabilities will launch the conference. First Lady Laura Bush has been invited to participate in the opening plenary.

Morning Plenary

The morning begins with an exciting panel discussion entitled *"Have we made progress in preventing Fetal Alcohol Syndrome? Insights and Lessons Learned from a 30-year History"*. Presenters include Kenneth Warren, PhD, National Institute on Alcohol, Abuse, and Alcoholism, National Institutes of Health; Kenneth Lyons Jones, M.D., University of California, San Diego School of Medicine; Raul Caetano, M.D., M.P.H., PhD., University of Texas School of Public Health; and Kathleen T. Mitchell, M.H.S., CCDC, National Organization on Fetal Alcohol Syndrome.

Day 2

Morning Plenary

Presenters include Alan Guttmacher, M.D., Human Genome Research Institute, National Institutes of Health; and Bartha Knoppers, LLB, DLS, PhD, University of Montreal.

Day 3

Closing Plenary

Presenters include Lex Frieden, MA, The Institute for Rehabilitation and Research. Temple Grandin, PhD, Colorado State University, and Senators Elizabeth Dole and Robert Dole have been invited to participate in the closing plenary.

A number of exciting presentations, workshops, and special events are being planned so please mark your calendar, register, and come join us in Washington, D.C. this summer!

Visit our website soon for the complete program and registration information at:

<http://www.cdc.gov/ncbddd/conference>



Preliminary Conference-At-A-Glance

(subject to change)

Sunday, July 25, 2004 – Conference Registration and Information Desk 12:00 noon—8:00 p.m.

8:00 a.m. — 5:00 p.m.	Ancillary Meeting* – Legacy for Children Annual Meeting
3:00 p.m. — 5:00 p.m.	Ancillary Meeting* – NCBDDD External Partners Group Meeting

Monday, July 26, 2004 – Conference Registration and Information Desk 7:00 a.m.—6:00 p.m.

7:00 a.m. — 8:15 a.m.	Continental Breakfast
8:15 a.m. — 9:30 a.m.	Opening Plenary: Welcoming Remarks Presenters: First Lady Laura Bush (invited) José F. Cordero, MD, MPH Director, National Center on Birth Defects and Developmental Disabilities Centers for Disease Control and Prevention
9:30 a.m. — 10:00 a.m.	Break and Refreshments - Exhibits Open
10:00 a.m. — 12:00 noon	Plenary: <i>“Have we made progress in preventing Fetal Alcohol Syndrome? Insights and Lessons Learned from a 30-Year History”</i> Facilitator: Kenneth Warren, PhD National Institute on Alcohol, Abuse, and Alcoholism Presenters: Kenneth Lyons Jones, MD University of California, San Diego School of Medicine Raul Caetano, MD, MPH, PhD University of Texas School of Public Health Kathleen T. Mitchell, MHS, CCDC National Organization on Fetal Alcohol Syndrome
12:00 p.m. — 1:30 p.m.	Poster Session with Authors and Workshops (Lunch on your own)
1:30 p.m. — 3:00 p.m.	Concurrent Session #1**
3:00 p.m. — 3:30 p.m.	Break and Refreshments
3:30 p.m. — 5:00 p.m.	Concurrent Session #2**
5:00 p.m. — 7:00 p.m.	Ancillary Meeting* – National Information and Resource Center Directors Meeting
7:00 p.m. — 9:00 p.m.	Reception

* Ancillary Meetings are generally by invitation only and are arranged by various individuals, groups, funded partners, or constituents.

**Concurrent sessions will consist of contributed papers and/or symposia sessions.



Tuesday, July 27, 2004 – Conference Registration and Information Desk 7:00 a.m.—6:00 p.m.

6:30 a.m. — 8:00 a.m.
8:00 a.m. — 9:30 a.m.

Networking Breakfast

Plenary:

Presenters: **Alan Guttmacher, MD**
National Institutes of Health
Bartha Knoppers, PhD (Invited)
University of Montreal

9:30 a.m. — 10:00 a.m.
10:00 a.m. — 11:30 a.m.
11:30 a.m. — 1:30 p.m.
1:30 p.m. — 3:00 p.m.
3:00 p.m. — 3:30 p.m.
3:30 p.m. — 5:00 p.m.

Break and Refreshments - Exhibits Open

Concurrent Session #3**

Awards Program and Luncheon

Concurrent Session #4**

Break and Refreshments

Concurrent Session #5**

Wednesday, July 28, 2004 – Conference Registration and Information Desk 8:00 a.m.—4:00 p.m.

7:30 a.m. — 8:30 a.m.
8:30 a.m. — 10:00 a.m.
10:00 a.m. — 10:30 a.m.
10:30 a.m. — 12:00 noon

Continental Breakfast

Concurrent Session #6**

Break and Refreshments

Closing Plenary:

Presenters: **Lex Frieden, MA**
The Institute for Rehabilitation and Research
Temple Grandin, PhD (Invited)
Colorado State University
Senator Elizabeth Dole (Invited)
Senator Robert Dole (Invited)

1:30 p.m. — 9:30 p.m.

Ancillary Meetings*

- National Council on Folic Acid Meeting
- Early Hearing Detection and Intervention (EHDI) Federal Interagency Advisory Committee Meeting
- NBDPN Executive Committee
- Disability and Health State Grantees Meeting
- Autism and Developmental Disabilities Monitoring (ADDM)
- Network and Centers for Autism and Developmental Disabilities Research Epidemiology (CADDRE) Surveillance Meeting

Thursday, July 29, 2004 – Conference Registration and Information Desk 8:00 a.m.—12:00 noon

7:00 a.m. — 4:00 p.m.
8:00 a.m. — 12:00 noon
8:00 a.m. — 5:00 p.m.

Ancillary Meetings*

National Council on Folic Acid Meeting
Disabilities and Health State Grantees Meeting
Autism and Developmental Disabilities Monitoring (ADDM)
Network and Centers for Autism and Developmental Disabilities Research Epidemiology (CADDRE)
Surveillance Meeting

* Ancillary Meetings are generally by invitation only and are arranged by various individuals, groups, funded partners, or constituents.

**Concurrent sessions will consist of contributed papers and/or symposia sessions.



General Information

Conference Cost

- Early Registration (including payment and form by June 15, 2004) \$195
- Regular or On-Site Registration (after June 15, 2004) \$225
- Student Rate \$ 95
- Continuing Education Credits \$ 50

Payment Method

Pay fees when you register on-line at:

<http://www.psava.com/ncbddd2004/registration>

VISA, American Express, and MasterCard are accepted, as are purchase orders or checks. Payment must be included with your registration. Registration includes all materials, access to sessions and exhibits, continental and networking breakfasts and breaks each day, the Monday evening reception, and the awards program and luncheon on Tuesday.

Participant Substitutions

If you are unable to attend the conference, you may send a substitute. Substitutions can be made at any time, including on-site at the conference for no additional fee.

Cancellations

Cancellations made in writing on or before June 30, 2004 will be refunded minus a \$75 administrative fee. No refund will be provided after the deadline.

Continuing Education Credits

Continuing education units (CEU's) will be offered for various professions based on an estimated 17.75 hours of instruction. Units will be given only to those persons who attend sessions and complete the required documentation. Participants can register for CEU's on-site. A fee of \$50 will be charged for those persons wishing to receive CEU's.

Hotel Reservation Information

The conference hotel is the Omni Shoreham Hotel, 2500 Calvert Street, NW, Washington, DC 20008, Telephone: (202)-234-0700 or for direct reservations: (202) 756-5125, fax (202)-756-5120. Checkin is 3:00 p.m./Check-out is 12:00 noon. For more information on the Omni Shoreham Hotel go to:

http://www.omnihotels.com/hotels/default.asp?h_id=6

We have blocked rooms for this conference at the following rates:

- Single Occupancy: (exclusive of taxes) is at the prevailing federal government per diem (subject to change), currently \$150.00.
- Double Occupancy: (exclusive of taxes) is based upon the prevailing federal government per diem (subject to change), currently \$170.00.

Reservations must be made directly with the hotel no later than Thursday, July 3, 2004, to ensure room availability and to receive the conference room rate.

To receive the conference room rate, you must inform the hotel reservation staff that you are calling for the group rate for the **NCBDDD Conference**.

All reservations must be guaranteed by a valid major credit card, which will be supplied at the time of reservation. Cancellations will be accepted prior to 12:00 noon (Eastern time), on the day of arrival. If the reservation is no longer required and is not cancelled prior to this time room and tax charges will be billed to the credit card on file.

Ground Transportation from the Airport

The hotel is located about 20 minutes from Reagan National Airport (and just 1/2 block from the Metro stop). You have several transportation options from Reagan National Airport. Take the Metro (yellow line in the direction of Mount Vernon Square) to Gallery Place/Chinatown. Change to the red line in the direction of Shady Grove. Take red line to Woodley Park/Zoo/Adams Morgan stop. Hotel is located half a block from the metro (fare is \$3). Or, take a taxi (about \$20) or the SuperShuttle from the Ground Transportation Level.

From Dulles or Baltimore/Washington airports take the SuperShuttle located in the Ground Transportation Level directly to the hotel. Taxis are also available at about \$60-80 one-way.

SuperShuttle fares are one-way:

To/from Reagan National	\$9
To/from Dulles	\$25
To/from Baltimore/Washington	\$35

Exhibits

Please plan to tour the exhibits in the Blue Room located in the hotel's East Wing. If your Organization would like to exhibit at the Conference, contact Angeline Lewis by phone at 404-633-6869 ext. 209 or by e-mail at a_lewis@psava.com.



Conference Check-In

The conference registration and information desk, located on the hotel's West Lobby, will be open the following hours during the week of the conference:

- Sunday, July 25, 2004
12:00 noon to 8:00 p.m.
- Monday, July 26, 2004
7:00 a.m. to 6:00 p.m.
- Tuesday, July 27, 2004
7:00 a.m. to 6:00 p.m.
- Wednesday, July 28, 2004
7:00 a.m. to 4:00 p.m. (ancillary meeting registration begins at 1:30 p.m.)
- Thursday, July 29, 2004
8:00 a.m. to 12:00 p.m. (ancillary meeting registration)

Special Activities

Continental and Networking Breakfasts and Breaks

Opportunities exist to network during the breakfasts and breaks planned each day.

Welcome Reception

A reception to welcome all conference participants will be held Monday, July 26, 2004, from 7:00 p.m. to 9:00 p.m. at the hotel. Don't miss this opportunity to network with colleagues.

Awards Luncheon

An awards program and luncheon is planned for all conference participants on Tuesday, July 27, 2004. This is an opportunity for CDC to acknowledge the outstanding contributions of its colleagues, partners, and others in promoting the health of babies, children, and adults, and enhancing their potential for full, productive living.

Other Fun Activities While in Washington, D.C.

Many exciting and entertaining activities are planned for the conference in Washington, D.C. A full-service spa and fitness center is available within the Omni Shoreham Hotel. Walking and jogging opportunities are available through Rock Creek Park adjacent to the hotel.

Other Places of Interest in Washington, D.C.

Adams Morgan Neighborhood: Centered on 18th Street and Columbia Rd, NW, Adams Morgan is synonymous with entertainment and diverse dining. Ethnic restaurants, nightclubs and bars line the two streets filled with vibrant Latino and African communities that lend an international flavor to this eclectic neighborhood.

Arlington National Cemetery:

America's largest national burial ground, with more than 600 acres of landscaped hills. Among the thousands of white headstones are the graves of President John F. Kennedy and the Tomb of the Unknowns. Open daily 8 a.m.-5 p.m. Free admission. Metro Arlington Cemetery.

<http://www.arlingtoncemetery.net>

Dupont Circle Neighborhood: The hub of cosmopolitan Washington. Victorian row houses and Beaux-Arts mansions have been restored to house embassies, international restaurants, art galleries, and museums. Some museums include The Phillips Collection, the Woodrow Wilson House, the Textile Museum and the National Geographic Society's Explorers Hall. Just a quick walk down Connecticut Avenue, culture and entertainment collide on the circle at the many cafes and shops.

Georgetown: Once a thriving colonial port, Georgetown is now a prime example of an intact historical community. Centered on Wisconsin and M Streets, NW, the community is most renowned for shopping, dining, and nightlife as well as the university that shares its name. Dumbarton House, Tudor Place Historic House and Garden, the C&O Canal, Old Stone House, and Dumbarton Oaks represent the area's history beyond the boutiques and antique shops.

Capitol Hill: Bustling with fabulous restaurants and cafes, shops and galleries, Capitol Hill is the place to dine, shop, and even celebrity-spot. Hill attractions include Botanic Gardens, Capitol Building, House of Representatives, Supreme Court, Library of Congress, and the Smithsonian Museums.

Old Town Alexandria: Once a principal colonial trading center and port, Alexandria's "Old Town," which is almost 50 years older than the city of D.C., is one of America's most historic communities. With over 200 restaurant and pubs in a fifteen-block radius, there's something for everyone.

Metrorail is the safest, cleanest, and most efficient way to get around D.C. Train lines are named for colors: red, yellow, blue, green, and orange. Metro opens at 5:30 am Mon-Fri and 8:00 am on Sat-Sun. Metro closes at midnight Sunday through Thursday and 2:00 am Fri-Sat.

<http://www.wmata.com>

For more information about Washington, D.C., visit: <http://www.washington.org>



Award Nomination Information:

Nominations are being solicited for the following awards:

- Effective Practices Award
- The NCBDDD Director's Outstanding Leadership Award
- The CDC Distinguished Service Award

Persons and/or organizations selected for each award will be recognized at the Awards Luncheon on Tuesday, July 27, 2004, in the Omni Shoreham Hotel's Regency Ballroom.

Nominations must be received no later than Monday, May 3, 2004.

The following guidelines should be used:

1. Complete all sections of the award nomination form on-line and submit electronically.
2. Use a separate form for each nominee and each award.
3. Describe your nominee's contributions related to the NCBDDD mission giving specific examples (limit to 500 words or less).
4. Provide the name of one additional reference who can provide supportive information and background.
5. Use the submission form included in this booklet (page 8) only if you are unable to submit your nomination electronically. If using the form from this booklet, keep your response limited to the information required on the form. The description of your nominee's contributions should be limited to one additional page.

An E-mail confirmation of receipt will be sent to the person completing the nomination form. Submissions made on-line will receive immediate confirmation of receipt by return E-mail. If you have not received the E-mail confirmation within 5 business days of submission, please call Angeline Lewis at 404-633-6869 ext. 209 to verify receipt.

Award Descriptions

Please take this opportunity to nominate and recognize those who have made significant contributions to address the causes of birth defects and developmental disabilities, to help children develop and reach their full potential, and to promote the health and well-being among people of all ages with disabilities.

Best Effective Practice

For effectively improving public health practice through effective use of NCBDDD data, epidemiology and applied research. This award recognizes individuals or organizational units who make significant contributions to public health practice at the community, state, and national levels through the effective use of data and epidemiology. The criteria for this award includes 1) importance of work, 2) contribution to practice, and 3) level of impact on the population.

NCBDDD Director's Outstanding Leadership Award

Recognizes outstanding contributions of an individual, team, or organization in the fields of: birth defects, developmental disabilities, disability and health, and/or hereditary blood disorders. Such contributions may include efforts with major impacts on public health related to the NCBDDD mission, outstanding lifetime achievements, or services and support of the NCBDDD mission deserving of special recognition.

CDC Distinguished Service Award

This CDC award is given to individuals or groups in recognition of their outstanding contributions to disease prevention and/or health promotion. Contributions to specific areas of public health, or special acts deemed particularly noteworthy, are recognized with this award.

You are encouraged to submit all nominations online at:

<http://www.psava.com/ncbddd2004/nominations>

Final Deadline for Nominations: Monday, May 3, 2004



NCBDDD 2004 Conference Awards Nomination Form

Submit your Award Nominations online at:
<http://www.psava.com/ncbddd2004/nominations>

All submissions must be received no later than 5:00 p.m. (Eastern) on Monday, May 3, 2004.

NOMINEE:

(Name of Nominee)

(Job Title/Position)

(Organization/State)

(Address)

(Telephone)

(Fax)

(E-mail)

NOMINATED BY:

(Name of person completing form)

(Job Title/Position)

(Organization/State)

(Address)

(Telephone)

(Fax)

(E-mail)

TYPE OF AWARD:

- ☐ Effective Practices Award
☐ NCBDDD Director's Outstanding Leadership Award
☐ CDC Distinguished Service Award

Background and Rationale: On a separate page, in 500 words or less, describe why this individual or group merits the award for which they are being nominated. Outline their demonstrated professional experience and contributions to the field of birth defects, developmental disabilities, disability and health, and/or hereditary blood disorders. Include one additional reference who can provide supportive information and background.

Submit this page and the one-page background and rationale by fax or mail no later than 5:00 p.m. Monday, May 3, 2004 to:

Professional and Scientific Associates
Attn: Angeline Lewis
2957 Clairmont Road, Suite 480
Atlanta, GA 30329
Telephone: (404) 633-6869 ext. 209
Fax: (404) 633-6477

Online Form at: <http://www.psava.com/ncbddd2004/nominations>



Conference Registration Form

CDC 2nd Conference on Birth Defects, Developmental Disabilities, Disability and Health, and Heritable Blood Disorders

Navigating Our Future: Aligning Strategies and Science

July 26-28, 2004

Omni Shoreham Hotel, Washington, D.C.

Please register online at <http://www.psava.com/ncbddd2004/registration>

Please check one: ☐ Dr. ☐ Mr. ☐ Ms.

Name: _____ Degree(s): _____
First M.I. Last

Job Title/Position: _____

Affiliation: _____

Address: _____

City: _____ State: _____ Zip Code: _____

Telephone: _____ Fax: _____ Email Address: _____

☐  **Special Needs/Request**

NCBDDD is committed to making the conference assessable to people of all abilities. Check here if you require assistance to fully participate in the meeting. Please attach a written description of requirements.

Registration Fees Payable to PSA:

- | | |
|---|-------|
| <input type="checkbox"/> Early Registration (on/before 6/15/04) | \$195 |
| <input type="checkbox"/> Regular/On-Site Registration (after 6/15/04) | \$225 |
| <input type="checkbox"/> Student Rate | \$ 95 |
| <input type="checkbox"/> Continuing Education Credits | \$ 50 |

Total All Amounts Checked Above \$ _____

Registration fees include conference materials, networking and continental breakfasts, afternoon refreshments breaks, the Tuesday Awards Luncheon, and the Welcome Reception.

Payment Information

Make your registration payable to:

Professional and Scientific Associates
2957 Clairmont Road, Suite 480
Atlanta, GA 30329

Telephone: (404) 633-6869

Fax: (404) 633-6477

Federal Tax ID: 52-1477-591

Payment Type:

☐ Purchase Order – PO # _____

☐ Check Enclosed – Check # _____

☐ Credit Card: ☐ Visa ☐ MasterCard ☐ American Express

Account Number: _____ Expiration Date: _____

Name of Cardholder: _____

Signature: _____

Invoices for purchase orders will be generated immediately upon registration and are payable upon receipt.

Cancellations and Substitutions

If you are unable to attend the conference, you may send a substitute. Substitutions can be made at any time, including onsite at the conference, for no additional fees. Cancellations made in writing on or before June 30, 2004, will be refunded minus a \$75 administrative fee. No refund will be provided for no-shows or cancellations received after June 30, 2004.

DEPARTMENT OF
HEALTH AND HUMAN SERVICES
Centers for Disease Control and Prevention
Atlanta, GA 30341-3717

Official Business
Penalty for Private Use \$300

Return Service Requested

FIRST CLASS MAIL
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Permit No. G-284



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July 26-28, 2004 in
Washington, DC*

**National Center on Birth Defects and
Developmental Disabilities Conference**